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THE RISKS OF THE TREATMENT OUTWEIGHED THE BENEFITS.

Dear Mr Milburn,

I am the partner of a co-infected haemophiliac who is infected with HIV, hepatitis C and hepatitis B through NHS blood products. His brother also a haemophiliac died of AIDS in 1986. I have written on many occasions via my MP Mr Jim Cousins to request a meeting either with yourself or Lord Hunt but it appears no-one wishes to speak with me! How surprising!

I have been trying for a number of years to persuade the Government to hold an open and honest public inquiry into the infection of hundreds of haemophiliacs with HIV and hepatitis viruses and for those haemophiliacs infected and families affected to be treat with compassion and recompensed for their suffering.

I have not as yet seen any comment from the Government on the statement to the press by Dr Peter Jones, a retired haematologist from Newcastle and world -renowned expert in his field. (see articles attached). Dr Jones is currently giving evidence to the Lindsay Tribunal, the public inquiry in Eire into how haemophiliacs came to be contaminated.

Could we please have a written press statement on this matter as soon as possible.

Dr Jones states very clearly that he was "forced" to prescribe imported plasma from high-risk sources such as skid –row, prisons, slums of Africa etc where the hepatitis rate alone could be up to 70 % higher than from unpaid, volunteer, British donors; a fact that was withheld from haemophiliacs until recently. He points the finger of blame at the Government whom he says has lied and he accuses the Government of a "cover-up" on this matter of contaminated blood.

We have considerable evidence that Britain ignored all safety warnings regarding hepatitis viruses, there is even a letter from a top heptologist in the States who wrote to William Maycock advising that Britain SHOULD NOT import factor concentrates from America. The World Health Organisation also advised this. The reason being that in 1975 the estimated hepatitis risk from imported plasma made from large donor pools was 100%, a fact NOT relayed to patients.

The figures are a tragic reality to-day as you can see from John Denham's answer to Jim Cousin's parliamentary question when he asked how many haemophiliacs who were infected with HIV were also infected with hepatitis C. The answer is 99%. The total number of HCV infected haemophiliacs is over 4,000.

Could the Government please stop misleading the public with the factually incorrect and utterly insensitive statement used by medical professionals and politicians alike that "the benefits of the treatment outweighed the risks". This might have been the case if we had used our own British products but the facts speak for themselves.

During a five year span from 1969 to 1974, before the wide-spread introduction of factor concentrates 71 haemophiliac patients died, not all from haemophilia. During a typical 5 year span when concentrates were widely used 413 haemophiliacs died from HIV, as mentioned above 99% being co-infected with hepatitis C. On top of this we need to be add the death figures for hepatitis C alone. There is a huge difference between 71 and 413 deaths in case you failed to notice this fact. Now it is extremely rare for a haemophiliac to die of a bleed but last year there were at least 23 deaths from HIV/hepatitis C and this will continue for years to come. What good is it having mobile joints if you are 6 feet under? Dead boys don't play football! Let's face it doctors and politicians were tunnel- visioned and made serious mistakes with regard to safety issues resulting in what we term the "haemophilia holocaust" which has decimated the haemophilia community.

It is incorrect to say that nothing could have been done prior to heat-treating of blood products. The single most effective safety measure prior to the introduction of heat-treatment was to stop using paid donors from other countries. That was the opinion of leading experts.

Are you going to force haemophiliacs into pushing for a criminal investigation such as that in Canada to seek justice? Even the ex-gratia settlement was a con. Why put a hepatitis waiver in an HIV settlement? Scotland did not feel that this was necessary as the settlement was nothing to do with hepatitis. NO haemophiliac in England, Scotland, Wales or Northern Ireland has received a penny so far via a legal settlement for hepatitis infection. The waiver was a cruel, calculated move to prevent further litigation for a virus haemophiliacs DID NOT know they had when they signed the waiver. They had NOT even been tested!

It was interesting to note that our old solicitor claims to have known nothing of the dubious sourcing of blood as described by Dr Jones. He took his advice from a much larger firm. To have come to a settlement agreement without this major evidence on the risks taken by doctors and politicians suggests that the settlement was seriously floored. Perhaps this needs to be investigated!

I am aware of the numerous letters that passed between David Owen and various civil servants where Mr Owen himself calls for an investigation into why his instructions with regard to self-sufficiency were NOT carried out in the mid – seventies. Do you really think you can cover this up for ever? If so you should plug your leaks better than you have been doing! Haemophiliacs have had enough and an increasing number of press have seen documentation and now realise the extent to which we have been deceived.

Please don't insult me by passing my correspondence on to Lord Hunt once again. I am sure he won't want to deal with me, probably too busy looking after the interests of the pharmaceutical companies. I will save you the trouble of passing my letter on as you usually do and send him a carbon copy. I am aware that Government is concerned over the recent "sensationalist press", yes the truth is shocking and the press will continue. We look forward to their coverage of our rally at Westminster on the 3rd of April.

Your recent statement says that what haemophiliacs want most of all is treatment. Yes they would love EFFECTIVE treatment but for many twenty years down the line with HCV infection it's too late. Please could you tell me what is the effective treatment if you have a non-responding genotype with regard to the experimental pegylated interferon/ ribaviron treatment, are co-infected and have advanced stage liver disease? If your answer is a transplant, how does an HIV positive haemophiliac who is immuno-supressed manage post-transplant (that is if they can access a liver) on a life- time of immuno-suppressants? Don't treat us like total idiots, we know a lot more than the Government about HCV, we live with it!

What haemophiliacs want is safe treatment, recombinant, to end post-code prescribing, a public inquiry and recompense, in other words we simply want parity with Eire who has successfully managed to provide ALL this to their haemophiliacs.

We are near to an election date and I am sure that the voters will be looking at how political parties deal with issues such as this when it comes to making their choice. At present the Government's attitude to the whole contaminated blood catastrophe has been to continue to withhold information and mislead the public.

Do you have any thoughts on why I have been told by a senior haematologist that by campaigning that I am opening up a can of worms and that I might receive death threats, that I have a son to think about and that attempts may be made to discredit me. Please tell me is it usual for this sort of information to be passed on during a consultation at an NHS hospital? The press don't seem to think so! Neither do they think it normal that doctors and those in the blood industry have been threatened whilst trying to highlight blood contamination issues.

Will the Government now hold a public inquiry? I look forward to your reply.

Yours sincerely

Carol Grayson

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Cc. Lord P Hunt (Of Kings Heath)
Lord Alf Morris (Of Manchester)
J Denham MP
Tony Blair MP
Jim Cousins MP
Press (Various)
Haemophilia Society UK